



Interviewee: **Despina Insogna**

Interviewee Number:

Interviewers: **Athena Aardweg and**

Tony Buba

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Interviewer: We start out by your giving your name and a little bit about your family. Wherever you want to start, that's where you can take it from.

Despina: Okay. My name is Despina Insogna and I was born and raised in Verona, Pennsylvania. I live in Penn Hills now. I'm married. My husband is J. J. and I have a beautiful two year-old daughter Amalia. She's my everything. She is my everything. I don't know what I did without her. I always tell her, "Mommy wasted a lot of time before she came along." I didn't realize how much time I had.

Interviewer: So, she's two, right?

Despina: She's two.

Interviewer: Let's talk about when she was born.

Despina: Amalia was born with Down syndrome. We didn't know, but we did know. When I was pregnant with her, I was pregnant at the age of thirty-four. And I have some minor heart conditions, so I had a lot of testing done early on in the pregnancy, because they were concerned that the baby wouldn't be able to grow, which you know, the pregnancy went great. She grew. She was fine. I had four ultrasounds, and the first ultrasound--you know, we were talking before you came in about the lack of compassion some of the doctors have.

The first ultrasound, the ultrasound tech--I guess they're not allowed to say a whole heck of a lot--and she left the room, who I had yet, had never met. This woman that my doctor referred me to for the ultrasound, she came into the room. She introduced herself and she said, "Well, there's some irregular measurements in your baby. You know, they're indicative of Down syndrome. So we're going to wait another couple of weeks, see if your baby grows, have you come back in. If we're still seeing that, we can do some further testing and decide if you want to terminate."

I couldn't believe somebody said this to me! I met you just three minutes ago and you're already telling me I might want to terminate my baby because she's not going to be our society's version of perfect. You know, my husband and I left that appointment just completely stunned. We didn't know what to say. We couldn't even talk.

I did go back a few weeks later, after I had talked to my doctor, and I said, "I really don't want to see this woman any more." I just never experienced anything like that with a doctor. I don't know what the dialogue was between him and her, but when I went back, she was certainly a lot more compassionate and a lot more pleasant to work with.

But that appointment, they said, "No, your baby grew. Her measurements are falling in line with what we expect to see, so we're not really worried about anything. We still recommend an amniocentesis."

But I said, "That's not going to change my mind. I'm not going to do that."

Then they did some blood work and the blood work came back that one of the proteins was high and that could be a Down syndrome indicator. We said, "Okay, it is what it is."

Again they asked if we wanted to do an amniocentesis and we said, "No."

The third appointment went fine, the third ultrasound. The fourth ultrasound, it was a totally different doctor that I had never met before and he said to me, "Your baby's thigh bone is a little on the small side. That could be a Down syndrome indicator." And then he looked at me and said, "Well, how tall are you?"

I said, "4'11", and he said, "How tall is your husband?"

My husband wasn't with me, and I said 5'3".

And he said, "Well then we're not worried about this. It's probably just constitutional."

So, I guess, in the back of our heads, we kind of knew that this was going to happen. Whatever. When I went into labor, I wasn't permitted to labor because of my heart condition and I wasn't permitted to have an epidural, so they had to knock me out completely to deliver the baby via C-Section and my husband wasn't allowed to be in the room. So I woke up to him asking the nurse, because he was holding her at this point, "Does she have Down syndrome?" Because he could see it.

And she said, "Well, they were talking about it in the Delivery Room but they took a chromosome study and they'll get back to you in a few days."

Nobody came to tell my husband, "Hey, this is what we think might be going on just so that you know." Of course, it's a congratulatory experience, but tell somebody, you know?

And it was actually several days before the chromosome study was confirmed but we already knew. She spent some time in the NICU, because she had some breathing issues but she's otherwise perfect and healthy.

Interviewer: Unfortunately, we've heard a lot about the hospital environment not being celebratory and saying, "Congratulations, you had a baby."

Despina: No, it wasn't. One of the NICU doctors was very candid with us, and you know, very forthcoming with information, and she didn't mince words, you know—I had one nurse come in and say, "Oh, she looks a lot like you. There is something about the eyes, but you have similar eyes to hers, so it's probably not Down syndrome."

And I was thinking, "Lady, it is what it is. I'm taking her home. She's mine."

Interviewer: And so you said she was in the hospital for a month?

Despina: No, no, just five days. She was in the NICU for five days. She had had what they call a dusky episode. She stopped breathing so they wanted to monitor her breathing, which was fine. I mean, she hasn't had any breathing issues since. She's been very healthy. She was born with a minor heart abnormality that corrected itself by the time she was four months-old. You know, with children with Down syndrome, open heart surgery is a reality, and that's certainly not what we wanted to see happen in this tiny little baby. But it corrected itself and, you know, she's really been fabulously healthy. You know, the occasional cold just like any other little kid.

Interviewer: So at the hospital did they give you any resources or support type of information?

Despina: They did. A social worker came in the following day. The doctors weren't confirming much with us, but they did send a social worker in to see us. The social worker gave us some information. I didn't know a lot about Down syndrome before we had her, and that first day they gave us a book. I read this book front to back that first day. My experience had been going to Special Olympics and volunteering. That was the limit of my experience. And they gave us some information. One of my coworkers, he has a daughter; who's... she's got to be about thirteen now, with Down syndrome. When he heard about Amalia, he called the Down Syndrome Clinic right away and asked the coordinator to call me, which she did and we got in. She was only six weeks old. ...to have her seen. The doctor was actually very surprised that we were in so quick. The parents that he's accustomed to seeing are in denial and he doesn't see the kids until they're about four, five and six months old. He was happy that J. J. and I, we were educating ourselves as much as we could right away about Down syndrome, what it was, what I could expect.

She learns a little bit differently. There's some physical conditions that we have to keep an eye on, but we all learn a little bit differently. She's wonderful. She has a spirit and an energy like nothing I've ever seen, not in any child.

You know, that was the other thing. I don't know if it's just, she's just a unique kid. But when I would volunteer at Special Olympics I used to think, "You know, they're so sad. Why are all these people so sad?" Then I realized they're not sad. I didn't take the opportunity to sit down and talk to anybody and to really get to know them and to see just how much spirit and energy they have. And I'm learning so much, you know. We go to the clinic and we participate in the Buddy Walk. I've met so many people and I've met so many individuals that do have Down syndrome, and there's nothing they can't do, you know?

We're just so poorly educated about what it is and you know, what to expect from it.

Interviewer: I think a lot of the parents have said that a lot of it they educated themselves on and went back to the doctor and said, "I'm seeing this right now."

The doctor is the medical professional, but a lot of people say it's really the parents that take on the whole educational role.

Despina: You live and breathe that child. And it's true, you know, the doctors and those books, they give you all that medical perspective.

There was a book I was looking at that the Down Syndrome Clinic themselves had given me. I don't think that book is more than ten years old, and I am just amazed at the terminology that they use.

Interviewer: Yeah, even in ten years it's changed.

Despina: Yeah. And to think that as early as ten years ago, when a child was born with Down syndrome, they would ask parents what institution do you want to put your child in? I couldn't imagine that. I could not imagine not bringing home this wonderful child.

I've learned so much, you know. The doctors, they give you their medical perspective, whether she had Down syndrome or not, they're always going to give you their medical perspective, but everybody's such an individual and everyone's so different. We have a multilingual family, and our first appointment, they said, "Well, you really want to focus on one language, because we don't feel that, our experience has not been positive with speech development in learning more than one language."

I walked away from there and said, "I can't imagine not giving her the opportunity to learn our languages." My mom's first language is Spanish, and she was born and raised in Cuba. It's just too natural for her and to ask her, she watches her a couple days a week and to ask her to try to switch into English and not give Amalia the experience of my mother. It just didn't seem possible. And she responds so well to my mom, she understands. Her receptive language is incredible. She understands when my mother is speaking to her in Spanish. She does what my mom asks her for. She knows what my mom needs.

Interviewer: So you were able to bring her home and I'm interested in what you just said about your mother. How did your family respond after the whole pregnancy situation of maybe, maybe not?

Despina: You couldn't have asked for anything more out of either one of our families. Everybody was just fantastic. It was never about Amalia was born with Down syndrome. It was about we have a new baby, Amalia.

Interviewer: I think she likes it that way. I'm assuming now she's getting therapy.

Despina: She has early intervention services.

Interviewer: Can you talk a little about that?

Despina: Yeah. She has early intervention services. It is a wonderful resource if you know how to use it, and if you have therapists that come into your home and care about your child. She has physical therapy, speech therapy, occupational therapy, and a developmental specialist that come in and see her. Thursdays are our busy day because she has two sessions every Thursday. She has speech therapy Tuesday evenings. And actually, she'll be graduating from that just before her third birthday. And then we'll probably keep on speech and physical, just to keep her pace with other children her age. I still haven't figured out how we're doing that one, but we'll figure it out.

The coordinator for the Down Syndrome Clinic is wonderful. She e-mails me. I mean she slams me with e-mails of programs and the Down Syndrome Congress, the National Down Syndrome Congress. There's lots of organizations out there, there really are. You have to know how to find them and how to use them to benefit you. There are resources out there.

Interviewer: I'm just curious. We work in community relations so we always talk about how much do you print, how much do people find online. How did you find the majority of the research you found?

Despina: Online. That was always my go-to, because that was available to me twenty-four hours a day, and if there was something that I couldn't confirm or wasn't real sure about, at least I had my information by morning, and I could at least contact somebody at that point. The social worker did provide us with some information, but it was, that's a tough time to start trying to provide anybody with that information. But I did get a lot online.

Interviewer: Does she go to pre-school?

Despina: No. My mom and my mother-in-law take turns watching her throughout the week, so that J. J. and I can work. And my sisters take turns with her on Saturdays, because I work on Saturdays. I make up that time on Saturday so that I can have Thursday off, to be with her for her early intervention services, and I'm not ready for her to go to pre-school yet.

Interviewer: The transitional phases are the hardest. More so for parents because you worry about what's going to happen or how do you choose. What's been the hardest part for you so far?

Despina: You know, the hardest part is I worry about the future. I worry about how people will treat her because she has Down syndrome, as she gets older. That's what I worry about. I don't worry about her, because she's strong, she's very willful, she's stubborn. She has what she needs to succeed. I'm not worried about that. It's what... It's people's perception of what she can and what she can't do. That's what I worry about. You know, she's healthy. Of course, like any mom, you worry about her health, but that's the thing that I'm forever worried about. When she goes to school, when she goes to work, when she goes to get a driver's license, I said it before. There's nothing she can't

do, but people are going to think she can't. And that's what I worry about, because I don't want her to ever feel like she's missing something, because she's not.

Interviewer: So how do we change that? It's education, but how? How do you make people realize that when you sit down with someone you don't automatically feel pity or like they can't do something?

Despina: It's one person at a time. I mean, it's you know, it's no different than all the other problems we see in the world today, racism, intolerance. It's the same thing, and we can only do it one person at a time. When, for whatever reason it comes up in a conversation with somebody who doesn't know me very well, and I say, "My daughter has Down syndrome." Everybody's first response is to say, "I'm sorry." I said, "Why? Why are you sorry? I'm not. I don't understand why you're apologizing to me. There's nothing to be sorry about."

And I'm very vocal. If I hear somebody say something that's inappropriate or ignorant or misguided, I let them know. She's very bright. She's got a lot to say. We're in trouble.

Interviewer: Yeah. You can tell once she starts talking! So what's the most inspiring part of this?

Despina: Her energy. She gets very, that is just, you come home after a long day and just that little face, and that laugh, and that smile and that energy that she has; and she's so happy to see you. That inspires me every day to do what I need to do. She inspires me.

Interviewer: This one woman, who is a friend of mine, her daughter is about 16 and she has Down syndrome. It'd be interesting if she gets a chance to come and talk to us. It would give a good perspective to hear from a 2 year-old to a 16 year-old. That's one of the things we're trying to do with these interviews is to get a variety of ages and perspectives so you can see exactly how people talk about those experiences.

Interviewer: Yeah, I'm just thinking the latest thing was with Usher Syndrome, and we were able to interview several people. One day it was with this age, but then we went to the next interview and based upon their experience, this is very common. I think that reminded us why looking at age groups and getting the parents and the really young ones and the adults who have been working full time.

Interviewer: One woman we interviewed had two children with Down syndrome. They're both adults. They're both living on their own. No, one is living by himself and the other is having a hard time getting an apartment but she wants to live by herself. She works at the Giant Eagle.

Interviewer; The difference is like you said, 10 years later you're still reading a book that talks about sending a child immediately into an institution, and that's not

even a thought. We're so far away from that in most families' minds at this point that that's not an option.

Despina: No, and I still, we still hope, God willing, that we'll have another baby. I still won't have any of the tests done. I've been blessed and she's a wonderful child. That's all I wanted. She's everything I wanted in a little girl.

Interviewer: The only response I got from one person was the pity. People either pity you or put you on a pedestal.

Despina: I don't need either one. I'm not doing anything spectacular, I'm a mom. Just like my neighbor next door or the person across the street. We're moms. These are our children. This is what we do. We take care of them, you know? We guide them and we educate them. Yeah, I'm not doing anything spectacular and there's nothing to feel sorry about.

Interviewer: Where have you gotten the most support from?

Despina: Family, you know, is wonderful. We both come from great families. We both come from close families--and that's all I need--my family. We have some great close friends, a small group of friends that we regularly associate with and Amalia is Amalia.

Interviewer: Is that a family name?

Despina: No. Amalia, I thought was Greek. There was a Queen Amalia in Greece in the 1800s, and after we named her, I happened to be researching it online and discovered she was English. She just happened to have reigned in Greece.

Interviewer: So it was Emily, right?

Despina: (laughter) I don't even know what it was, but years ago when I used to dance, we used to wear a costume that was called the Queen Amalia, and I always loved that name, and I couldn't wait to have a girl to name her Amalia.

Interviewer: Any advice for other parents?

Despina: They're your child first. The disability or whatever you want to call it, that's just a very small part of who they are. You know, she's a person, she has feelings. You can't ever think, "My child has this disability. They can't do something." Yes, they can, and Amalia has proven to people over and over again how wrong they can be. There is nothing she cannot do.

She commands attention. Anywhere we go, she commands attention. There are beautiful babies out there and no less than ten people a day stop her to tell her how pretty she is, or how funny she is, or just to say hello.

Interviewer : She's very expressive too.

Despina: She's got a lot to say with her face.

We're learning how to stand.

Interviewer: Is there anything else that you want to make sure people realize or understand?

Despina: One thing, I'll say it again, don't think that there's something your child can't do. I have 100% full expectations for her. She will go to school. She will go on to secondary school. She's going to drive a car. She's going to work. She's going to be independent, there's no reason why she can't be.

Your children, I don't care if it's Down syndrome, I don't care if it's cerebral palsy, I don't care what it is, they will amaze you. Their will will amaze you.

Interviewer: Are there any other questions?

Interviewer: How did you hear about the project?

Interviewer: Of course, how could I forget that one? I always ask that one.

Despina: I first heard about it a few months ago from Sheila Cannon. She's the coordinator of the Down Syndrome Clinic. She had sent out e-mails and I kind of set it aside. We have a lot of time constraints, with work, both of us working full-time; and then I got a second e-mail, and I made myself another note and set it aside because I wanted to look into it. I hadn't had a chance to read anything that had been sent out by the project, and then there's another individual, his name is Kurt Kondrich, who, and I met him through e-mail. He said, "This is a spectacular thing that they're doing, and I encourage you to participate in it if you can."

And I said, "I really have to... This is the third or fourth time that this has come across my desk, and I need to do something with it, because I said in the beginning I would," and then I made that phone call.

Interviewer: Kurt was one of the first people we interviewed.

Interviewer: Yeah, and we were still looking, so he spread the word. We've had people who have really helped us.

Despina: And he did, and so did Sheila.

Interviewer: Yeah, and we wanted to get not the typical people who are interviewed. We wanted to represent the families and individuals and the friends who are going through this and understand it.

Interviewer: Where do you work?

Despina: I work for Parkvale Bank.

Interviewer: Where at?

Despina: I work in Verona, which works great for me because at least I'm close. When she was born I was working in Greensburg and that wasn't fun at all. That wasn't fun at all for mama.

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I'm going to e-mail her some photos.